Equity of access to renal transplant waiting list and renal transplantation in Scotland: cohort study

Papers

Equity of access to renal transplant waiting list and renal transplantation in Scotland: cohort study

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Abstract

Objective To examine the access to the renal transplant waiting list and renal transplantation in Scotland.
Design Cohort study.
Setting Renal and transplant units in Scotland.
Participants 4523 adults starting renal replacement therapy in Scotland between 1 January 1989 and 31 December 1999.
Main outcome measures Impact of age, sex, social deprivation, primary renal disease, renal or transplant unit, and geography on access to the waiting list and renal transplantation.
Results 1736 of 4523 (38.4%) patients were placed on the waiting list for renal transplantation and 1095 (24.2%) underwent transplantation up to 31 December 2000, the end of the study period. Patients were less likely to be placed on the list if they were female, older, had diabetes, were in a high deprivation category, and were treated in a renal unit in a hospital with no transplant unit. Patients living furthest away from the transplant centre were listed more quickly. The only factors governing access to transplantation once on the list were age, primary renal disease, and year of listing. A significant centre effect was found in access to the waiting list and renal transplantation.
Conclusions A major disparity exists in access to the renal transplant waiting list and renal transplantation in Scotland. Comorbidity may be an important factor.

Introduction

The number of people who develop end stage renal failure and require renal replacement therapy is ever increasing. In Scotland (population 5.2 million), the number of newly identified cases has increased from 60 per million population in 1989 to 108 per million population in 1999.[1] Kidney transplantation is the most successful and cost effective treatment for renal failure and should represent the gold standard, yet not all patients receiving dialysis are suitable for transplantation, and there is evidence that selection criteria vary widely.[2–4]

The Renal Association has highlighted the importance of ensuring that there is equity of access to transplantation irrespective of age, sex, race, district of residence, and social welfare.[5] Since the inception of the NHS in Britain there have been concerns about equity of access to health care, and priorities in access to renal transplantation have come under scrutiny.[6–8] A sequence of potential barriers along the pathway to transplantation has been shown.[9] Growing evidence, mainly from the United States, shows that transplantation rates are associated with a patient's health status as well as socioeconomic and geographical factors, and that these vary significantly across different ages, races, and sex.[10–13] We investigated the relation between socioeconomic and geographical factors and access to the renal transplant waiting list and renal transplantation in Scotland to determine whether similar discrepancies exist.

Methods

From the Scottish Renal Registry and UK Transplant databases we identified 4523 adults aged 18 or over starting renal replacement therapy in Scotland between 1 January 1989 and 31 December 1999. They were followed to placement on the waiting list, transplantation, death, or end of the study (31 December 2000). We excluded 408 patients (9%): 44 had pre-emptive renal transplants, 123 were placed on the waiting list before starting dialysis, and 241 had missing data.

The clinical outcomes were access to the waiting list for transplantation and access to a kidney graft. We used univariate and multivariate Cox proportional hazards regression analysis to investigate the factors associated with the likelihood of being placed on the waiting list and undergoing transplantation. The results are presented as relative risks with 95% confidence intervals. Kaplan-Meier curves were used to determine the time when 50% of the patients were placed on the waiting list or underwent transplantation. We considered a 5% level as being significant, and the analyses were carried out with SPSS software, version 9.0.

Access to the transplant waiting list

Variables considered were patient's age when starting renal replacement therapy, sex, social deprivation, distance from the patient's home to the transplant centre, primary renal disease, type and year of first renal replacement therapy, centre where first renal replacement therapy was undertaken, and the centre where the patient was placed on the waiting list for transplantation. Social deprivation was assessed with the Carstairs score, a combination of four variables (male unemployment, car ownership, social class, and overcrowding), derived from the census and calculated for each postcode.[14] The scores are classified into seven categories from 1 (least deprived) to 7 (most deprived). Primary renal disease was grouped into five categories: glomerulonephritis, interstitial nephritis, diabetic nephropathy, multisystem disorders, and other or unknown diagnosis.[1] Age was divided into five groups: 18-34, 35-49, 50-59, 60-65, and >65 years. The centre effect was investigated firstly by grouping the renal units according to the transplant centre to which they are geographically allocated and, secondly, by looking at whether or not patients started dialysis in a renal unit situated in a hospital with a transplant centre.

In the absence of a variable in the renal registry that could identify patients never suitable for placement on the waiting list

and transplantation, an intention to treat approach was used to calculate the time it took 50% of them to be placed on the list. All patients starting renal replacement therapy were considered suitable for placement on the waiting list. This method, although statistically correct, does not give a true indicator of how long it takes for someone suitable for transplantation to be put on the list. Therefore as an indicator of current clinical practice, we performed a separate analysis, taking into account only patients put on the list within the study period.

Access to transplantation

The same variables were analysed along with the time from first dialysis to placement on the waiting list. Age was considered at the time of being put on the list rather than at the beginning of renal replacement therapy. We calculated the median time of access to transplantation from being listed, excluding the periods of suspension, during which patients are not considered for transplantation.

Table 1 Multivariate Cox proportional hazards model showing relative risk of access to waiting list for transplantation in Scotland

Variable	No (%) of patients (n=4115)	Relative risk (95% CI)	P value*
Men†	2397 (58.3)	1	
Women	1718 (41.7)	0.81 (0.73 to 0.90)	<0.0001
Age group:			
18-34†	446 (10.8)	1	
35-49	664 (16.1)	0.75 (0.65 to 0.86)	<0.0001
50-59	721 (17.5)	0.44 (0.38 to 0.51)	<0.0001
60-64	564 (13.7)	0.21 (0.17 to 0.25)	<0.0001
>65	1720 (41.8)	0.07 (0.06 to 0.08)	<0.0001
Deprivation category:			
1 (least deprived)†	203 (4.9)	1	
2	518 (12.6)	0.69 (0.53 to 0.91)	0.008
3	903 (21.9)	0.72 (0.56 to 0.93)	0.011
4	1035 (25.2)	0.66 (0.51 to 0.84)	0.001
5	616 (15.0)	0.57 (0.44 to 0.75)	<0.0001
6	532 (12.9)	0.62 (0.47 to 0.81)	0.001
7 (most deprived)	308 (7.5)	0.54 (0.39 to 0.74)	<0.0001
Primary renal disease:			
Primary glomerulonephritis†	672 (16.3)	1	
Interstitial nephritis	856 (20.8)	0.78 (0.68 to 0.90)	0.001
Multisystem disease	988 (24.0)	0.54 (0.45 to 0.64)	<0.0001
Diabetes	674 (16.3)	0.50 (0.42 to 0.58)	<0.0001
Other or unknown	925 (22.5)	0.60 (0.51 to 0.72)	<0.0001
First renal replacement therapy:			
Haemodialysis†	2899 (70.4)	1	
Peritoneal dialysis	1216 (29.6)	1.46 (1.32 to 1.64)	<0.0001
Transplant centre:			
Centre 1†	516 (12.5)	1	
Centre 2	400 (9.7)	0.88 (0.71 to 1.09)	0.24
Centre 3	811 (19.7)	0.44 (0.36 to 0.53)	<0.0001
Centre 4	2388 (58.0)	0.38 (0.32 to 0.45)	<0.0001
Distance to transplant centre:			
0-50 km	3511 (85.3)	1	
50-100 km	302 (7.3)	1.12 (0.92 to 1.40)	0.25
>100 km	302 (7.3)	0.69 (0.55 to 0.85)	0.001
Year of first renal replacement therapy, per year		0.95 (0.93 to 0.97)	<0.0001
Renal unit in hospital with transplant centre:			
Yes†	2351 (57.1)	1	
No	1764 (42.9)	0.72 (0.65 to 0.80)	<0.0001

All variables not shown, but similar relative risk observed.
*Cox regression.
†Reference category.

Results

Between 1 January 1989 and 31 December 1999, 4523 adults started renal replacement therapy in Scotland. Of these, 1736 (38.4%) were put on a waiting list for renal transplantation and 1095 (24.2%) received a kidney transplant by the end of the follow up period. The mean age at the onset of renal replacement therapy was 57.73 (SD 16.03) years, whereas the mean ages at placement on the list and undergoing transplantation were 46.60 (SD 14.14) and 44.30 (SD 13.52) years, respectively. Overall, 50% of patients receiving dialysis were placed on the waiting list in 2.84 years whereas 50% of those on the list underwent transplantation in 1.74 years (95% confidence interval 1.55 to 1.92).

Access to the waiting list

Table 1 shows the relative risk of access to the renal transplant waiting list for the variables analysed in the intention to treat analysis.

Sex and age

Women were less likely to be placed on the list (relative risk 0.81) and had to wait significantly longer before they were (table 2). Overall, 1720 (41.8%) patients were aged over 65, but the older the patient, the lower the rate of being put on the list and the longer the time spent on dialysis before listing.

Social deprivation, primary renal disease, and type of first renal replacement therapy

The likelihood of placement on the waiting list decreased with increased social deprivation. Patients in group 7 (most deprived) spent the longest time on dialysis before being put on the list. Of the 4115 patients on dialysis, 674 (16.4%) had diabetic nephropathy. These patients had the lowest rate of listing, with less than 50% being placed on the list within 10 years of starting dialysis (table 2). Patients with diabetes who were eventually listed, however, spent the shortest time on dialysis before being put on the waiting list (table 2). Overall, 30% (1216 of 4115) of the patients started renal replacement therapy on peritoneal dialysis. These patients were placed on the waiting list more quickly and had a 46% better chance of listing than those on haemodialysis.

Renal unit and transplant centre

When all 11 renal units were grouped according to the transplant centre to which they are geographically allocated, patients were more likely to be placed on the waiting list and waited a shorter time if referred to centres 1 and 2 (see tables 1 and 2). Patients starting dialysis in the four units situated in a hospital with a transplant centre (57% of the cohort) were more likely to be placed on the list (relative risk 0.72) and waited a significantly shorter time than the other patients.

Distance to transplant centre

Patients living furthest away from the transplant centre (>100 km) were more likely to be put on the waiting list, and this was sooner after starting dialysis than patients living closer to the unit. We found a 5% reduction in the rates of listing for each year closer to the end of the follow up period.

When the analysis was restricted to those patients who were actually placed on the waiting list (rather than the intention to treat analysis), all variables except sex remained important factors for access to the list.

Table 2 Access time to waiting list for 50% of all patients (years) and 50% of those eventually placed on list for renal transplantation (months)

	All patients (n=4115)		Patients on waiting list (n=1526)	
Variable	Time (years) to 50% on waiting list	P value*	Time (months) to 50% on waiting list	P value
Men	2.14	0.007	5.95	0.7†
Women	5.03		5.95	
Age group:				
18-34	0.52	<0.01	5.28	<0.01‡
35-49	0.59		5.16	
50-59	1.16		7.08	
60-64	>9.33§		7.56	
>65	>11.01§		7.08	
Deprivation category:				
1 (least deprived)	2.94	0.0018	5.04	<0.01‡
2	3.13		4.80	
3	1.69		5.76	
4	2.4		6.00	
5	4.38		6.60	
6	2.80		6.72	
7 (most deprived)	5.13		6.72	
Primary renal disease:				
Primary glomerulonephritis	0.79	<0.01	5.52	<0.01‡
Interstitial nephritis	1.09		5.88	
Multisystem disease	9.39		8.04	
Diabetes	>10.59§		5.40	
Other or unknown	>10.32§		6.84	
First renal replacement therapy:				
Haemodialysis	4.5	<0.01	6.36	0.001†
Peritoneal dialysis	1.23		5.28	
Renal unit in hospital with transplant centre:				
Yes	1.94	<0.01	5.16	<0.01†
No	4.64		6.72	
Transplant centre:				
Centre 1	0.88	<0.01	3.84	<0.01‡
Centre 2	0.98		4.68	
Centre 3	3.73		6.84	
Centre 4	5.03		6.60	
Distance to transplant centre:				
<50 km	3.29	0.0283	6.00	0.04‡
50-100 km	1.99		5.04	
>100 km	1.47		6.00	

*Log rank test.
†Mann-Whitney U test.
‡Kruskal-Wallis test.
§Less than 50% of patients listed by this time point, by end of study.

Access to transplantation

Older patients were less likely to undergo transplantation and spent longer time on the active waiting list (tables 3[3] and 4). Patients with renal failure of unknown origin and those with multisystemic disease had the least chance of undergoing transplantation. They also spent over two years on the active waiting list before receiving a transplant.

We found a significant centre effect on the likelihood of transplantation and time spent on the active waiting list. This seemed to be due to the outlying effect of centre 2, where patients had a 43% less chance of undergoing transplantation than those in centre 1. The chance of transplantation decreased by 4% for each year closer to the end of the study period.

Table 3 Multivariate Cox proportional hazards model showing relative risk of access to renal transplantation

Variable	No (%) of patients (n=1526)	Relative risk (95% CI)	P value*
Age group:			
18-34†	362 (23.7)	1	
35-49	455 (29.8)	0.77 (0.65 to 0.91)	0.0025
50-59	383 (25.1)	0.69 (0.57 to 0.83)	0.0001
60-64	156 (10.2)	0.64 (0.49 to 0.84)	0.0012
>65	170 (11.1)	0.45 (0.33 to 0.61)	<0.0001
Primary renal disease:			
Primary glomerulonephritis†	395 (25.9)	1	
Interstitial nephritis	443 (29.0)	0.90 (0.76 to 1.07)	0.22
Multisystem disease	234 (15.3)	0.77 (0.62 to 0.97)	0.0278
Diabetes	226 (14.8)	0.81 (0.64 to 1.01)	0.06
Other or unknown	228 (14.9)	0.75 (0.60 to 0.94)	0.0126
Transplant centre:			
Centre 1†	258 (16.9)	1	
Centre 2	167 (10.9)	0.57 (0.42 to 0.78)	<0.0001
Centre 3	286 (18.7)	1.18 (0.92 to 0.51)	0.18
Centre 4	815 (53.4)	0.92 (0.74 to 1.15)	0.48
Year of placement on list, per year		0.96 (0.93 to 0.98)	<0.0001

*Cox regression.
†Reference group.

Discussion

Major differences are apparent in access to the renal transplant waiting list and renal transplantation in Scotland. Similar disproportions have also been identified in the United States, Canada, and Europe.[11 12 15 16]

Age is a major factor influencing access to transplantation, an increase in the age of the patient being associated with a reduced likelihood of placement on the waiting list and transplantation The sharper decline in access to the waiting list indicates that the main selection process takes place at this stage and may be attributable to higher comorbidity in older people. Once on the list, the difference is diminished, as healthier candidates have already been selected and differences are probably influenced by other factors such as the structure of the system for allocating organs and the decision making process.

Table 4 Time of access to transplantation from being placed on waiting list (days)

Variable	No (%) of patients (n=1526)	Time (days) to 50% receiving transplants	P value*
Age groups:			
18-34	362 (23.7)	446	<0.0001
35-49	455 (29.8)	623	
50-59	383 (25.1)	738	
60-64	156 (10.2)	800	
>65	170 (11.1)	1521	
Primary renal disease:			
Primary glomerulonephritis	395 (25.9)	526	<0.0001
Interstitial nephritis	443 (29.0)	520	
Multisystem disease	234 (15.3)	851	
Diabetes	226 (14.8)	697	
Other or unknown	228 (14.9)	836	
Transplant centre:			
Centre 1	258 (16.9)	634	<0.0001
Centre 2	167 (10.9)	1442	
Centre 3	286 (18.7)	465	
Centre 4	815 (53.4)	623	

*Log rank test.

Sex is an important determinant of access to the waiting list. A similar sex difference has been reported,[17] and similar rates (relative risk 0.84 for women) were observed in the United States.[11] Explanations for these differences include patient preference, sex selection by health professionals, socioeconomic and health status, non-compliance, and sex based differences in family preferences for transplantation.[18–20] Once on the waiting list, women have a similar probability to men of receiving a transplant, suggesting that the allocation system in the United Kingdom may have eliminated differences between the sexes, unlike other transplant programmes, where there is a persistent disparity.[15 17]

The rates of placement on the waiting list declined with increasing socioeconomic deprivation. Reasons for these discrepancies apply to both patients and health professionals. Patients who are socioeconomically disadvantaged may have higher comorbidity, and medical non-compliance may be more common.[21] It is conceivable that these patients may not appreciate the advantages of transplantation and therefore may not be good advocates for themselves when it comes to choosing the best treatment option. It is also possible that healthcare workers are biased to manage patients in ways that allow some to be listed sooner than others.[22] Unlike other analyses, our study shows that once on the waiting list, patients have an equal chance of transplantation, irrespective of the socioeconomic status.[10] Most of the potential reasons may therefore be eliminated with the assessment process.

Patients with diabetes have the lowest rate of access to the waiting list for transplantation, which may be due to additional and more severe comorbidity. Although transplantation rates for these patients are better than their listing rates, the likelihood of further complications may underlie the persisting differences in access to transplantation.

The type of first renal replacement therapy (peritoneal dialysis versus haemodialysis) also predicted access to the waiting list. This finding should be interpreted with care, as the type of first dialysis is chosen according to the patient's general status, primary disease, tolerance, or preference, and many patients will switch between dialysis modalities throughout their treatment.

A longer waiting time on dialysis before transplantation has been correlated with a poorer outcome, therefore, patients with end stage renal failure should undergo transplantation as early as possible.[23] We found no correlation between the chance of transplantation and the length of time spent on dialysis before placement on the waiting list, suggesting no discriminatory effect against those referred later in the course of their renal disease.

Differences in access according to geographical criteria have been previously reported. We showed that the further away from the transplant centre patients lived the quicker they were placed on the waiting list. No differences were found in access to transplantation after listing.

This analysis showed a significant centre effect, with patients having a 28% better chance of listing when they started dialysis in a renal unit in a hospital with a transplant unit. This persisted when the renal units were grouped according to the transplant centre to which they were geographically allocated. The centre effect on access to transplantation seemed to be artificial and was due to the outlying effect of a particular centre. We can only speculate about the reasons behind differences between centres, but it has been suggested that centre characteristics, size and organisational aspects, the attitudes of healthcare staff towards transplantation, and training may be implicated.[4 19] This effect may be eliminated in the United Kingdom with the introduction of clinical practice guidelines for evaluating candidates for transplantation, such as those used in the United States and Europe.[21 24]

Comorbidity may account for some of the differences we found, but we could not examine this effect as insufficient data were available. Evidence from the United States shows that the addition of comorbid factors in analyses does not alleviate the effects of sociodemographic variables.[10] Racial differences in access to transplantation have been known for over a decade, but we were unable to analyse these owing to the lack of data on ethnic origin in the UK databases.[13]

A sequence of potential barriers exists along the pathway to transplantation.[9] This study has shown that for factors such as sex and socioeconomic status, the barrier seems to be at the waiting list stage rather than at transplantation, whereas for factors such as age and primary renal disease, differences persist at both stages. The current data did not allow an exploration of the various issues, which may explain these differences, and therefore studies designed to address these factors are needed.

What is already known on this topic

Potential barriers along the pathway to transplantation are apparent in several countries

Transplantation rates vary across different ages and races

Selection on to the renal transplant waiting list and undergoing transplantation are associated with health status and socioeconomic factors

What this study adds

For the first time in the United Kingdom, inequities in access to the renal transplant waiting list and renal transplantation have been identified

Inequities in access to the renal transplant waiting list and transplantation in Scotland are associated with socioeconomic, demographic, and geographical factors

These inequities may exist elsewhere in the United Kingdom because of similarities in management of patients with end stage renal failure and transplantation

Conclusions

Inequities in access to the renal transplant waiting list and renal transplantation are apparent in Scotland. Since the management of end stage renal failure, referral patterns for transplantation, and the transplantation process are similar throughout the United Kingdom, these inequities may exist elsewhere.

It is important that patients with advanced renal disease and those who care for them are aware of the factors associated with successful listing and transplantation. The transplant community often concentrates on graft and patient survival rates after transplantation, but for the patient, access to this service may be the greatest hurdle. Therefore, fairness in access should be pursued with the same dedication that new immunosuppressive drugs or better dialysis regimens are sought.

Contributors: GCO designed the study with JLRF, compiled the database, performed some of the analyses, and wrote the manuscript. AHS collected the postcode data and updated the entries in the renal registry. RJJ extracted the relevant data from the UK transplant database and provided statistical advice. HB performed the statistical analyses and contributed to the statistical sections of the manuscript. JLRF designed the study with GCO and revised the manuscript; he will act as guarantor for the paper.

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Ethical approval: This study was part of a research project that was approved by the Lothian research ethics committee (research ethics subcommittee for medical and clinical oncology; reference No LREC/2000/4/163).

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